

AGING - COPING STRATEGIES

ELAINE BOURKE, MSW, DASW

**A paper presented at the Workshop
"Aging - An Innovative Approach Towards the Year 2000"
February 15, 1989
Edmonton, Alberta**

Keynote Address - "Innovative Approaches to the Year 2000" Workshop hosted by the Charles Camshell General Provincial Hospital, Edmonton, Alberta, February 15, 1989 - Elaine Bourke

This morning, Mary, in presenting the demographics of our society, stressed that Canadians should view the increased longevity and growing numbers of older people not as a problem, but as a triumph of our society.

I have been asked me to address the topic, "Aging - Coping Strategies". Ten years ago, I would have spoken of the resilience, strength, humour and courage on the part of older people, including the institutionalized frail elderly with whom I work. They have infected me with their optimism. I would have described programmes which support these strengths and anticipated future planning and policy decisions which would have ensured a more secure and comfortable future for Canada's older population.

However, during the past five years, there have been indications that our society is becoming frightened by the alleged implications of the imbalance in the number of old people in the population. Financial constraints, scarcity of resources and the need for rationing of health and social services are being reported in the media, off-set against the needs of the elderly. The articles read as if they were ledger sheets juxtaposing the needs of the elderly against anticipated costs.

I believe that we need to be very concerned about how our society will address the political, economic, social and ethical implications of an aging society. How we as Canadians will cope. What coping strategies we can evolve during the next decade.

We are lucky. The 1990's will be a decade of reprieve - a ten year "time out". It is the period during which the smallest number of elderly, those of us born during a period of relatively low birth rate, will be supported by the largest population cohort in history - our children - the "baby boomers". During the next decade, if our economic situation does not weaken, the demands of the elderly upon the financial coffers should not be unmanageable.

Until the year 2010, we will have the opportunity to approach the increased aging of our society as a challenge, put the changing demographics into perspective, face the ethical and social dilemmas squarely, and make decisions based on reality and with concern for all segments of our population.

This morning, I want to look at some of the issues which have already begun to foster negative attitudes toward the elderly, and how many of these issues misrepresent the values and preferences of the elderly population. I will conclude with some of the innovative developments in problem solving that hold promise for our ability to formulate coping strategies for the future.

A S I D E

I FIND IT DIFFICULT TO BELIEVE THE RAPID INCREASE IN THE AVERAGE LIFE EXPECTANCY IN THIS CENTURY. BETWEEN THE YEARS 1900 and 1980, THE AVERAGE LIFE EXPECTANCY INCREASED MORE IN NORTH AMERICA THAN THE AVERAGE LIFE EXPECTANCY ON EARTH FROM THE BRONZE AGE TO 1900, A PERIOD OF 2,000 TO 3,000 YEARS. NO WONDER WE HAVE BECOME AWARE OF THE AGED AS A SIGNIFICANT SEGMENT OF THE POPULATION.

(Pamela Cluff, "Countdown to the Twenty-First Century", in the Quarterly, a Journal of Long-Term Care, OAHA, April, 1983.)

During the last 20 years, society has experienced an enormous surge of human energy, directed towards social change, particularly in the area of care for the elderly. The initial awareness of the elderly as a group in the 1960's, coupled with strong economic growth at that time, sponsored a variety of solutions in care for the elderly. These included the development of policies, programmes and legislation, as well as facilities and services. The 1960's awareness and growth continued into the mid 1970's. Today, these solutions are still in place and are a resource which we continue to use.

But that surge of growth eventually moderated and now appears to be undergoing a considerable review, as shifting political and economic pressures affect the system.

The economic implications of demographic changes have become matters of increasing debate over the past few years with, sometimes shrill expressions of alarm about the long-term health of the economy and, in particular, the ability to even maintain living standards as the working age population is faced with the economic burden of supporting the elderly.

We must be concerned about the present and future economic well-being of all Canadians. We must be very concerned about the growing tendency of our media, government, and other interested bodies to shift the blame for existing problems onto the aged population. Headlines such as "AGING TREND MAY USE UP ALL HOSPITAL BEDS", or "GOVERNMENT SHUDDERS AT THE COST OF GREY POWER" will affect negatively the attitudes of other segments of the population toward the elderly.

Not long ago, elderly people were stereotyped as uniformly poor, hopeless, helpless, and deserving of public generosity. More recently, the image has been changing. Many commentators now profile the elderly as a rich, greedy, self-serving group that neither needs nor deserves governmental largesse. The picture is of a materialistic, financially comfortable cohort. This group has been titled the "WOOPIES" (well-off older people), and Canadian business representatives are attending seminars across the Country on how best to target this group.

There also have been disconcerting statements on the part of health care providers. Recently, a physician's address to the Saskatchewan Health Care Association was reported in both the Toronto Star and the Medical Post. One headline was "UNREASONABLE DEMANDS BY PATIENTS THREATEN HEALTH SYSTEM"; the other, "TODAY'S HEALTH-CARE SYSTEM HEADED DOWN THE DRAIN". The presentation appeared a sincere, impassioned appraisal of some of the problems within the health care system. However, it stated that the public has to decide whether it wants a Cadillac health care system - where everyone is entitled to everything medicine can offer - or a Volkswagon system of basic acute care and emergency services. The physician favoured a "modified Volkswagon" system, where deserving patients get the best for free.

In his opinion, a 35 year old father of two should not have to pay for a heart transplant.

But a wealthy, 75 year old smoker who is an alcoholic should pay if he wants one and should not get special favours - such as the only available heart - if he agrees to pay.

In this illustration, it is evident that concern for the cost of health services had moved from a general discussion to a specific age-related criterion of how health services should be allocated. Would a wealthy,

alcoholic, 35 year old, single smoker not be an appropriate comparison? Or is being 75 years of age to be construed as an additional vice? I do not want to belabour the point, but it is imperative for us to be aware that statements such as this may indicate a devaluation of the aged person, and certainly constitute bias against interventions when applied to the elderly.

The fear of the impending bankruptcy of our medical and social service programmes, and of competition for scarce resources have generated ethical, social and political issues which have been articulated in the 80's; are being debated now, and must be acted upon if our society is to cope rationally with a rapidly aging population and its impact upon our society.

We must make certain that irrational fears are not translated into irrational social policies.

Canada's health care system has been under attack by almost every segment of society. Nearly all health care experts agree that a crisis is on its way. Costs of health care are escalating much faster than inflation. The projection is that health care threatens to bankrupt the government some day, and it is already eating up funds that used to go to other programmes.

The present health care system and delivery models have not been designed for demand pressures of the magnitude expected when the aging of the population reaches its peak in Canada. Not only will the increased number of aged affect our health care system, the system will also be affected by the developments in high technology medicine. The great advances in health care in recent years have come from these developments. Once the infectious diseases had been controlled, or eliminated, further improvements in health have depended heavily upon technology, although changes in lifestyle, particularly in the case of heart disease, have made a contribution also.

For the health care system, old age and high tech are not compatible. Continuing increases in the elderly population will result in increased use of hospital beds by very old people and a reduction in bed space available to the remaining population. That trend is contrary to the needs of a system based on high tech applications, procedures, costs and expectations.

In addition, many of these high tech applications will be available to the elderly, thus accentuating their bed requirements for recovery and rehabilitation.

Throughout this decade, opinion has been expressed that constant innovation in high technology medicine when (D. Callahan) applied to life extending care of the elderly is a blessing that too often turns into a curse. The argument is that technological advances have been heavily responsible not only for the increase in life expectancy, but for the steady increase in chronic disease that has also accompanied that increase. Technology has also had an important role in the escalating of health care costs.

Just four years ago (in the "Journal of the American Geriatric Society"), David Thomasma wrote that this geriatric imperative to extend life has created a world-wide crisis in advanced countries not only in terms of the cost of care, but also, in terms of assessing the quality of life and the achievement of goals.

He continues that "Two major efforts are required on our part. The first is establishing an ethically adequate care delivery system for dependent persons, especially one that is within economic reason for younger generations. The second effort is establishing guidelines for the degree of health care treatment to be given to the very old. The two efforts require criteria for establishing appropriate candidates for the care that is available, or for terminating care. Thomasma's concern was that the medical community has developed no rational way to decide what treatment to give and what to withhold, exclusive of "heroics".

Ethicists have been debating these issues, as well as those around the finitude of life, openended health care, indefinite life extension, quality vs. quantity of life, and the rationing of health care.

Until into this decade, these ethical questions concerning the ending phase of life had not been debated publicly. More recently, there has been a great deal of public interest, professional and lay. Hospitals have set up ethics' committees; one Toronto hospital has established an Ethics' Centre; universities and governments have established special programmes. While writing this paper, I saw a notice of a conference sponsored by the Saskatchewan Gerontological Association to be held last week. Its topic was "Ethical Dilemmas - Today's Reality, Tomorrow's Burden". The National Film Board created a series of films, each of which present an ethical dilemma for professional caregivers. Both sides of the issue are presented in the film, but the final outcome is left for the audience to decide. The accompanying brochure states the rationale for the production as "modern

science has given us vast powers to shape human life, from the fertilization of the embryo to the moment of death. But science has not provided the answers to 'when', 'how' and 'why' its 'wonders' should be employed, nor who will make the decision".

Dr. Evans of the University of British, Columbia has posed four questions that must be debated as the age bulge of the year 2000 approaches:

1. Just what medical care should cover for an aging population?
2. Who decides what is medically necessary?
3. What procedures are necessary or even beneficial? AND
4. Who shall be the arbiter when expert opinion regards a service as useless or even harmful, but the doctor and patient want it?

There are general concerns about the medicalization of our society. In a 1988 article in the New England Journal of Medicine, Arthur Barsky alerts his colleagues to the paradox of medical progress. He points out that there is no one-to-one correspondence between objective health status and the subjective perception of healthiness. He cautions his fellow physicians to bear in mind the negative side effects that can accompany an intensified emphasis on health and heightened expectation of medical care. He states that society currently devotes enormous amounts of time, money and effort to preserving our health, but the substantial improvements in health status have not been accompanied by improvements in the subjective feeling of healthiness and physical well-being.

Dr. Barsky did not attribute these changes of expectations to the self-centredness of the individuals within our society, but many service providers and policy makers do.

We are being cautioned continuously from many quarters that "unreasonable demands by people who think good health is a right are endangering Canada's health care system, that we must learn that health is a gift, there are no instant cures, and hospitals aren't baby-sitting services". Since it seldom happens that parents leave their children, for an undue length of time in hospital, it can only be concluded that the reference to baby-sitting refers not to babies but to the aged.

Such accusations, as health costs are scrutinized, overlook the cultural climate which encourages more attention on the part of all individuals to their bodies, their symptoms and their state of health.

Health is industrialized and commercialized in a fashion that enhances many people's dissatisfaction with their own health. The mass media have placed an increasing emphasis on health, sometimes mobilizing deep-seated fears about disease, and, insecurity about health and longevity.

In planning health care services, it is important to note that in spite of this cultural climate, studies of elderly people, in which individuals are asked to rate their health status, find consistently that the majority tend to feel healthier than their medical problems would indicate. One researcher noted that elderly individuals tend to agree that they are "in good shape for the shape they are in".

It is this more positive, subjective sense of healthiness which should make a good match between the elderly and the anticipated spread during the 1990's of health maintenance organizations, independent health facilities, community health organizations. If we do not try to force a match, this subjective sense of healthiness may even be responsive to the health promotion programmes.

I discovered early in working with elderly people that when I wished an individual a happy new year, the response would always come back "a happy and a healthy year. Health is the most important". In our younger years, we take health for granted. Older people do not. With good health, enough money, social supports and transportation to carry out necessary tasks and get to social activities, life is pretty good for most elderly people. The diminishment of any one of these attributes can seriously affect the individual's lifestyle and satisfaction. Once you need assistance in accomplishing any of the activities of daily living, it is necessary, if you are to remain in the community, to have support whether formal or informal. The issues in community support are very different from those in the health care system. The big difference, and the reason that governments at all three levels have established the priority of community services, is that current community services cost a great deal less.

The government's thrust toward community care has both ethical and social implications. Dr. Sheila Neysmith has reported that although the public policy prioritizing community care has been established for some years, the proportion of resources going to institutional care remains at \$9 for every \$1 being put into community care programmes. While there has been a gradual development of home care/support programmes across Canada, the

total picture is one of uneven development of the service package, and incomplete distribution of services across and within provinces. Services in urban areas are far more extensive than in rural areas within all provinces. Programmes are not only uncoordinated and fragmented, but often available only to those who can pay for them.

When, in contrast, the health care system in Canada is so well integrated and coordinated, why are established community services so disconnected and unreliable? There is suspicion that this may not be an accidental occurrence, and that the emphasis on "community care" is actually a euphemism for "family care", which again gets translated into "care by a female family member".

Those of us concerned for the welfare of all members of our society must insist that policy makers and programme planners not be misled by the current movement that suggests that traditional family supports have the capacity and desire to fulfill the full range of needs of the functionally impaired aged living in the community. Without minimizing the critical contributions of relatives, friends and neighbours, the limits to their ability must be recognized.

It is still expected that women will be the "caregivers" in addition to carrying all of their former responsibilities. In practice, community care policies have paid very little attention to the needs felt and expressed by caregivers. Government has done very little to support their caring efforts actively. Instead, it has confined the community care services to crisis or casualty intervention. This places a penalty on caring and rewards the breakdown of a caring relationship, while justifying non-active intervention through appeal to the ideological assumption that it is "natural" for the family to provide care, and especially "natural" for women to do so.

There are sound political, economic and social reasons why the social services should be sensitively integrated into the operation of informal care networks. The problematic issue concerns the basis on which this policy is implemented. There is danger of viewing informal support networks as a universal panacea for the problems - economic, organizational and operational - of the health and social services.

It is time that the politicians called a spade a spade, and were frank with the public about the inevitable fact that in the future, families will have to take more responsibility for supporting their parents in the community for longer periods of time and, therefore, through more fragile periods of health. There simply will not be institutional beds available to meet care needs at the entry level of care previously assured. We can't build that many more and we can't fund that many more. Already we have seen dramatic changes in the length of waiting lists for long-term care facilities, and the greatly increased proportion of cognitively impaired applicants for whom support in the community has broken down because of the overwhelming demands placed upon family caregivers.

If families are to provide care, they need enabling supports. Such supports would include day care, respite care, meals-on-wheels, caregiver groups, and financial remuneration possibly in the form of a tax credit. These would allow some options for both the old person and family members providing the care. The alternative can only result in an increase of stress on those families least able to cope. Studies on elder abuse have identified loss of control on the part of well-meaning family caregivers, stretched beyond their coping capacity, as a contributing factor.

In advocating support for the caregivers, we need to sensitize the community to what responsibilities women may be juggling in modern society.

In the January issue of the supermarket magazine "Family Circle", an article making predictions for the next decade suggested that the expression "The Sandwich Generation" would come to replace the expression "The Me Generation". A cartoon showed a young woman, knees buckling and arms outstretched, balancing an elderly woman on one hand and a child on the other. The article was very upbeat, but we who work with elderly people and their family members know from experiences that the stresses and demands from other generations on those in their late 40's, 50's, 60's, and even their 70's can become very burdensome, and indeed place the caregiver at risk.

For the first time in history, a fourth generation occurs in many families due to changes in the population during the 20th Century.

Such extended families may have three or four living grandparents, with all members competing for the resources of time and energy within the family. In our society, many of the older adult children, and their spouses, have

full-time jobs of their own, whereas in the previous generation, the wife would have been at home. Many are experiencing their own chronic disorders, or may be widowed or divorced. Then we have a new phenomena, wherein the third generation, the young adult grandchildren, i.e., my generation's children, are likely to leave home later than their parents did and to return home more frequently to live for periods of time - sometimes accompanied by their young children.

A comprehensive network which balances informal and formal home care services will have to give close attention to how task assignments are allocated between the two support systems. The successful maintenance of older people in the familiar setting of their own homes will ultimately be determined by the capacity of these two helping elements to work together, and to recognize the difficulties inherent in the respective responsibilities.

If within the next decade we do not come to grips with a manageable, integrated health and welfare approach to our elderly citizens, we stand to create a society divided by age. A term which has recently entered the political vocabulary is "intergenerational equity". In turn, this concept has led to another "intergenerational conflict" referring to competition between the elderly and the young for scarce resources. There has been a tendency to set the needs of dependent groups against each other rather than questioning the distribution of income in society itself. The directors of Canadian Pensioners Concerned were told by a policy advisor of the Federal Ministry of State for Seniors that "Canadian seniors will have to fight just to keep the benefits they now have". She was suggesting that this organization, which has an estimated 350,000 members, should increase its strength as a lobbying movement. Inherent in this advice was concern that the established rights of older Canadians could be challenged.

Four years ago, a Republican Senator in the United States helped establish the youth advocacy group A.G.E. (Americans for Generational Equity), with the mission to advance the claims of the young and counterbalance the powerful gray lobby.

In Ontario, we are being warned that unless the provincial treasury can get control of the spiralling budget, there isn't going to be enough money to pay for quality education for the young.

The potential for a full-blown conflict between competing needs of the young and the old will be fueled by an accompanying myth that the elderly are economically well-off and consequently are exploiting the present generation of earners. For the past 15 years, even as their parents grew more financially secure, young workers have faced declining real wages, rising taxes, high interest rates and prohibitive housing costs.

The removal of a mandatory retirement age in many workplaces has been seen as keeping jobs from youth and also holding back the middle-aged adult from higher paying, higher status positions. These are realistic concerns. However, some of the attitudes are not reasonable. A popular recent view is that elderly homeowners are wealthy. However, if you are older in Toronto and your 1964, \$20,000 house is now worth \$250,000, that doesn't add a cent to your disposable income unless you sell. Then, unless you move to an area well removed from the urban centre, far from friends, neighbours and services, you will not have improved your financial position. Yet to many younger couples, unable to afford a home in which to raise their families as their parents did, it must seem very unfair.

Twenty-four years ago, Dr. Robert Butler wrote his book "Why Survive? Being Old in America", in which he articulated the plight of the aged who were assumed to be universally frail, senile and burdensome. Those who followed Butler have helped to change society's perception of the elderly population from a homogeneous to a heterogeneous group, from dependent to mainly independent, and from inactive to active. In less than 25 years, we have taken Whistler's mother out of her shawl and rocking chair, and have put her in a chair-lift, on Whistler's mountain, in a trendy ski outfit. We may have set her up for a tumble.

One of our most pressing tasks must be to present the reality of aging and the aged. We need to bring the elderly back into the continuing life process that views aging as a normal continuum across years, and old age as the ending phase of life.

We still have several years to develop an approach which takes into account the values and the preferences of older people. We have to learn to listen to what they want and what they think they need.

The life goals I hear articulated consistently by older people are:

1. to be independent;
2. to live in your own home;
3. to enjoy your family and not be a burden on your family members;
4. to have opportunities for social interaction with people your own age;
5. to have available and accessible transportation;
6. to have medical and social services accessible and delivered in an understanding, respectful way;
7. not to suffer needlessly;
8. to have a natural death when the time comes;
9. to see grandchildren be successful.

It seems to me that society's coping strategies should be geared to helping elderly people to realize these goals. They do not sound like unrealistic goals nor impossible demands. I do not hear older people demanding or even wishing for an increased lifespan. Nor do I hear them speak positively about high technological advances for the aged - for the young yes, but not for the really old. When they say "I hope that in my lifetime they will have found a cure for cancer or heart disease", they usually are not thinking of themselves but of younger generations. They pray that their suffering will not be extended through artificial means. On the other hand, they tend ruefully to accept what they see as growing old - the twinges of arthritis, stiff knees, some hearing loss, changes in vision. Not the acute illness, nor severe sensory or functional loss, of course,

but what are seen as inconveniences with which you can learn to live. They are also prepared to take physical risks beyond those allowed by family and professional caregivers.

Let us design programmes and services for real people, not based on our projections about what we would want when we are old, or to meet the expectations of high tech. Perhaps if we got back to the basics, we could provide satisfactory services which support the goals subscribed to by older people and keep spiralling costs in check.

A. The aged person needs to feel independent and wants to live in her own home.

Let us start with Housing. It is assumed that almost 64% of Canadians over 65 years own their own homes. Most of them want to live there for the rest of their life. If maintaining the house becomes too great,

they want to move to their own apartment. They want to live independently. But many homes are not accessible for older people as their functional capacity diminishes. Not being able to negotiate one's living accommodations sometimes contributes to elderly individuals applying to live in costly institutions.

In 1981, Roger Diab, an architect with the Design Division of National Health and Welfare, presented a paper at the International Congress of Housing in Vienna. In his introduction, he stated:

"As our societies move closer along the path to the year 2000 and beyond, our governments realize the difficulties in providing the increasing number of the elderly segment of our population with the substantial services to meet their needs, mostly because issues dealing with the elderly have often been examined and treated in isolation."

"For instance", he asked, "how would a new approach for housing help alleviate the burden of the health network?"

During the past five years, the Design Division has developed guidelines for accommodations for elderly Canadians, from the adaptation of established homes to provide a safe, accessible and manageable environment, through semi-independent facilities to long-term care facilities. These guidelines for architects and planners are based on an holistic perspective. The CMHA has also established guidelines and in conjunction with the National Advisory Council on Aging and Canadian Association in Gerontology has organized seminars on future housing issues and developments in the light of the aging of Canada's population.

Last October, the Financial Post ran an article, "Seniors' housing boom: aging population spells bonanza for developers". It began, "In the space of three years, seniors' housing has progressed from an almost unknown market to one of the hottest that Canada's developers can imagine." It continued that "developers have gradually cottoned on to the fact that this generation of seniors can choose where and how they want to live. Instead of seeing seniors' housing as government-sponsored, institutional nursing homes, developers are talking retirement condos and exclusive seniors' villages."

The article went on to speak of some very innovative designs. The Japanese idea of movable walls and partitions in lightweight materials, and another idea of a precast, autoclaved ceramic panel that costs a tenth that of traditional materials and can be used inside and outside, not needing insulation.

These make design changes as simple as picking up a wall and moving it.

The retirement community in Airdrie, Alberta, by La Vida Communities Inc., built around a health care facility was mentioned also. People that purchase homes there also acquire part ownership of the community's recreational facilities.

If you wish to and can afford to be part of the age-restricted private retirement housing developments, you will, within the next few years, have a number of very interesting choices.

The majority of elderly people will not benefit from this knowledge nor from the enthusiasm that has been generated within Canada, unless governments assist with a continuum of housing options. We have excellent, knowledgeable and experienced people in Canada who can give guidance, from that of adapting an individual Home to meet its aging owners' needs through "Accessory Apartments" - a two unit dwelling that can be easily converted within an existing single home or for Granny flats. Taking another route, through a senior citizen apartment to group home to a minimal care apartment complex. There can be a variety of alternative environment or levels of care on a single site. These campus settings and retirement villages often feature a full range of choices, from small cottages to nursing home rooms. Such arrangements permit the aging individual to move from one level to another and back as health conditions change, while remaining within the same management pattern and social network. This concept is called "Aging In Place".

The need is there, the knowledge is there, the design guidelines are there. In the next 10 years, the buildings must be there if we are to provide elderly individuals with acceptable alternatives to institutional living and save society money in the long run.

Innovative European groups have developed some very interesting projects. In Paris, some mid-town apartment houses whose primary tenants are elderly, have had their main floor converted to provide a seniors' social centre and a sick bay. These meet the social and nonacute medical needs of the building's clientele.

B. The aged desire to have medical and social services accessible and delivered in an understanding, respectful way.

In addressing this need, the noted gerontologist Elaine Brody ("Service Options in Congregate Housing") states that within the next 10 years, we need to implement the accepted goal of an adequate long-term care system, including institutional and community services. It should be coherent and comprehensive. It should include interdisciplinary assessment; a spectrum of facilities providing options for an extremely diverse population, criteria for matching the individual to the most appropriate service, linkages among facilities, and services, to facilitate orderly movement along the continuum of care as changing needs dictate. It must be developed and accessed in partnership with the elderly individual and his family, and it must ensure to the greatest extent possible that the individual remains in control.

G. ~~GOAL~~ - The elderly want to enjoy their family and not be a burden.

Generally, family members care about each other. The abandonment of the elderly by their adult children even when separated by great distances has been proven a myth. Families provide most of the care to the elderly in Canada. And they do it with love, frequently to the point of risk of their own health and interpersonal relationships. Assistance is usually first provided in the parent's home, then in an adult child's home.

If families are to provide care, particularly in a way which helps to free the elderly individual from the fear of being a burden, they need enabling supports, particularly respite care.

A study of respite care was conducted by Zigler and Carden. Their findings and recommendations were published in a report, "Supporting Families Who Support Seniors: Respite Care in the Community".

They identified the various situations in which respite care is needed to support the efforts of families to care for their relative, either on a temporary or a continuing basis:

- on a short notice, in the event of illness or emergency in the family
- throughout the day to allow family members to attend other responsibilities or work outside the home
- up to 24 hours a day as necessary on occasion
- during occasional vacation periods to give the family and the dependent person a break.

One form of respite care is the traditional adult day programme, designed primarily to serve individuals who are limited physically and psycho-socially, to help them to maintain maximum functioning in the community. During the five or six compact hours that the person is in the programme, the services may range from rehabilitation to nursing and social services, and include recreation, dietary, socializing, education, personal care, exercise, transportation, and other therapeutic services that help maintain function and independence. However, for day care to be an effective programme, it cannot be limited from 9:00 a.m. to 5:00 p.m. for the clients, social worker, or the nurse. A comprehensive care plan must include assistance for the participants in managing their lives during the hours and days when the day programme is not open.

The greater the need for physical, social and cognitive supports, the more services will be required. As the population served and the very nature of the level of care required, more closely resembles institutional care than community care for the independent elderly, then day programmes should be seen as an adjunct to a long-term care facility. Our experience at Baycrest in the year and a half that the Special Day Care pilot project has been functioning is that the only viable alternative for care for the severely cognitively impaired members who are no longer able to manage in the day programme is admission to a long-term care facility. A programme of this type when attached to such a facility has the advantage of the individual being familiar with the setting and the setting familiar with the individual, thus minimizing the problems in relocation should admission become necessary.

An increasing number of long-term care facilities have allocated beds for respite for periods ranging from two to six weeks.

The Respite Study noted previously identified models for viable community-based alternatives to institutional and commercial respite care. Some of these are:

- The "In-Home Model" which is least disruptive to the older person because the respite care providers go to the individual's residence.
- In a "Host Family Programme", the dependent person temporarily moves into the home of another carefully matched family or individual. The host family receives a retainer and reimbursement for expenses while the family is charged a user fee.
- In the "Residential Model", the agency maintains small group homes or apartments in the community for respite care use.

We need to convince government to establish a comprehensive system of community-based respite care, which would assist the elderly to meet their goal of not being a burden on family members, and help families to cope more effectively in their efforts to keep their parents at home where they want to be.

Some other strategies aimed at helping family caregivers develop better coping mechanisms are illustrated in the paper in your package which was presented in November 1988 at the Canadian Association of Gerontology by Sheila Smyth, the Director of Baycrest's demonstration project "Caring for the Caregivers".

D. The aged want to die a natural death with dignity, retaining some measure of control as long as possible.

Ideally, a person would remain physically and psychologically intact through the 8th and 9th decade, then die quietly without a long period of illness. But the reality may be the opposite. People may have a drawn-out period of debility, with medical services keeping people alive, but keeping them neither healthy nor happy.

In recent years, there has been growing movement on the part of individuals to be in control of their life up to and including its end. D.N.R. orders are now on medical charts, as are letters asking that no

"heroic" measures be instituted to prolong life, and the concept of "living wills" is discussed openly. Although living wills are not legal in Canada, they are in 41 of the United States.

There is an increased emphasis on palliative care of the individual which concentrates on the relief of pain within a caring and responsive environment during the terminal phase of life.

The First International Conference on the Palliative Care of the Elderly is being held in Toronto on May 4th. Speakers from North America and Europe will discuss clinical, legal and ethical aspects of the practice of palliative care.

In thinking about the barriers to providing an optimum level of health and social services to the future elderly, it occurred to me that some of the ripple effects from high technology could improve the provision of services to the elderly by locating them within a familiar community framework.

Potential impacts of high tech development have been identified as:

- 1) The increased application of new equipment and techniques which will dramatically change the role of regional/referral hospitals, vis-a-vis that of local community hospitals. (This will mean that community hospitals will have less of a role in acute care.)
- 2) The changing role of hospitals and the continuing trend toward specialization will result in the concentration of specialists in urban areas.
- 3) Acute care hospitals will increasingly emphasize rapid patient turnover, which will intensify the need for home care and home support services, or for alternative placement facilities.
- 4) High tech will follow patients into their homes, including such items as home dialysis, heart monitors, respiratory aids, computer-controlled environment and other equipment which requires professional monitoring.

Should these changes take place, and certainly it is happening in the downtown areas of some large Canadian cities, what will the role of smaller community hospitals, rural and suburban, be? What will happen to the way in which the elderly and others receive care? Will large mega-hospitals

operate all departments on a 24-hour basis in order to make costly technology more cost-efficient? With a focus on speedy in and out, will the psycho-social needs of patients receive consideration? Will there be opportunity to recuperate or time for effective discharge planning, or will the patient be transferred to community hospitals for these services?

We know that the large and impersonal urban hospital is frequently not responsive to the needs of the individual at the best of times. A change in its pacing and an increase in the use of technocracy could put the frail elderly individual at risk.

For the smaller community hospital, which sees this change as a challenge rather than as a threat to its (survival), the potential for taking a leadership role in community health promotion could be exciting.

Health promotion has been defined as the enablement of individuals and communities to increase their control over factors which affect their health. It looks as if the key concepts of the '90's will be those of "wellness" and "health promotion".

The health promotion framework was presented by the Minister of Health and Welfare two years ago in the publication Achieving Health for All. Its three strategies were:

1. Fostering Public Participation
2. Strengthening Community Health Services
3. Coordinating Healthy Public Policy.

In a discussion of the second strategy, the document states:

"A health promotion and disease prevention orientation means that community health services will have to focus more on dealing with the major health challenges identified. For example, it assumes that there will be a greater emphasis on providing services to groups that are disadvantaged. Furthermore, it takes for granted that communities will become more involved in planning their own services, and that the links between communities and their services and institutions will be strengthened.

In these ways, community health services will become an agent of health promotion, assuming a key role in fostering self-care, mutual aid and the creation of healthy environments. This will involve coordinating programmes much more closely with those of social services in order to maintain momentum in the health promotion effort. Given the present range to their responsibilities, it is only logical that community health services should play this expanded role in promoting the health of communities."

Many community groups are opposed to health promotion programmes delivered by hospitals which are seen as cold, antiseptic and lacking interest in old people. However, it is the hospital which has the management expertise; the experience with a team approach, a working relationship with community health and social services, is a familiar building and is usually serviced by public transportation.

If the hospital does not wish to host the programme, it should be encouraged to play a leadership role in bringing the community services and organizations together for planning and providing management expertise during the development and implementation stages as well as offering inpatient and outpatient services as appropriate.

Yesterday, I visited the Charles Camsell Hospital and was impressed with its evidence of humanity. I believe that it is the kind of hospital that could give successful leadership to organizing a health promotion programme in its community because it is built upon a history of innovation and responsiveness to changing community needs.

There are very creative and innovative developments occurring, including some very unlikely partnerships. For example:

There has been a partnership between C.M.H.C. and the Canadian Manufactured Housing Institute. In a jointly sponsored poll, they asked Canadians about their interest in a Granny or garden flat for elderly relatives. The Gallop Poll showed 30% of respondents would buy one or wanted one for a relative. Industry experts in Canada were amazed as they had expected only 2% of people to like Granny flats. Then the C.M.H.C. announced that it would subsidize the \$30,000 to \$35,000 units for needy seniors. As a

result, Canada could have two million Granny flats by 2010. The flats are cheap because there are no land costs. In addition, they are portable and once no longer needed, can be moved elsewhere.

In the United States, there is a beginning partnership between employers and trade unions focused on employees with care-giving responsibilities for elderly relatives. It has been recognized that those who care for the elderly may face many of the same problems as do employees with young children.

Corporations are becoming increasingly aware of the significant and growing number of employees who struggle with the dual burden of meeting their job responsibilities and providing support and care to the elderly family member.

Some companies have already begun to develop innovative programming that will assist employee caregivers. Such benefits, they expect, will raise productivity, reduce absenteeism and allow them to retain valued employees who might otherwise quit. Travellers Corporation has offered lunchtime support groups, flex-time hours and an information fair for employees to meet with social service experts. Pepsi Co. provides seminars and a handbook on the care of the elderly. Remington Products of Bridgeport, Connecticut pays half of the cost of "arent sitters" who can take over for employees on evenings and weekends. In California, some companies are providing adult day programmes within their settings for relatives of their employees.

It has been suggested that "elder care", that is, those personnel policies aimed at employees with dependent parents, may be the employee benefits issue in the 1990's.

There are also programmes promoting an intergenerational partnership. Within many schools and communities, leaders are exploring ways to bring together retirees with skills and time to spare, and young people in need of training and guidance. The assumption that one generation can serve as a resource rather than a rival to another holds far more promise than any call to arms.

In closing, I would like to emphasize that Political strategies for the 1990's and enlightened leadership must come to terms with the prevailing politics of limitation, where we assume that we cannot help everyone and therefore, by default, leave people to fend for themselves. A politics of equity is required by which we attempt to respond to social problems and use government as the primary leader in devising solutions. How that will be done and when is uncertain, but the 1990's will provide an opportunity to redirect our energies and renew a social commitment to the entire society (Torres-Gil, F.M., "Process, Politics and Policy", Generations, spring 1988).

EB:bf
eb7/8